Transitioning through Life Stages: Growing up with a Special Health Need

Lynne A. Wolfe, MS, APRN, BC
Metabolic Nurse Practitioner
Genetic Consultation Service
Yale School of Medicine

Metabolic Diseases Today

- 300-1500 known Inborn Errors of Metabolism
- 50 % of them have been discovered in the last 25 years and more continue to be discovered
- Incidence of 1:4000 live births
  (1000 live births/year)
- Metabolic disorders are a major cause of chronic illness in childhood

Impact Inherited Metabolic Disorders

- Account for 5-6 % of SIDS cases
- Require Life-long care !
- Now reaching Childbearing Age
- Increased Maternal risk of HELLP syndrome or Fatty Liver of Pregnancy
- Adult Sequelae – Learning problems, Vision loss, Cardiomyopathy, Peripheral Neuropathy, Chronic Liver disease (?), Depression & Anxiety disorders, pregnancy

Impact Inherited Metabolic Disorders

- Children with metabolic disorders are hospitalized 3-4 times more often than other children
- Account for 12% of Pediatric Admissions (50% of Pediatric Admissions have a Genetic Disease)
- Account for 55% of overnight stays
- Increase LOS on average of 3 days
- Incur 184% of Inpatient costs
- 4-5% higher in hospital mortality rates
- 40% of overall Childhood mortality related to Genetic diseases

Importance of Definitive Care

- Costly, poor outcomes when not treated
- Collectively, not that rare
- More and more are treatable
- Full characterization can be used for future Prenatal Diagnosis
- Provides opportunity to future care planning

A team is needed to raise these children

- Parents/other family members
- PCP – Medical Home
- Metabolic Team
- PT, OT, SLP (local Early Intervention team)
- Developmental Pediatrician
- Gastroenterology
- Cardiology
- Opthalmology
- Neurology
- Transplant Team
- Special needs Dentist
- Pharmacist/Medical Supply company

How did we get started ?

- Olmstead Act of 1999 operationalized Americans with Disability Act 1990 (ADA)
  - "reasonable efforts" by States
- Presidents New Freedom Initiative 2001
  - Increased assistive technology access
  - Increased educational opportunities
  - Promoted home ownership/community involvement
  - Encouraged "integrated" workforce
  - Increased transportation options

How did we get started ?

- Surgeon General's "Call to Action" 2005
  - Assess trajectory of disabilities
  - Increase knowledge of Healthcare providers
  - Supported self-management & health promotion
  - Increased Healthcare & Social Services access

How did we get started ?

- President Bush's Executive order February 2008
  - Implement strategies to improve health of American youth including encouraging Inter -agency cooperation and improved community -based resources
  - Encouraged development of youth oriented websites & support groups.

Maternal and Child Health Bureau (1998)

Define Children with Special Health Needs as:

"Those children who have or at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who require health and related services of a type or amount beyond that required by children generally."

Healthy People 2010 Goals

- Families of children and youth with special health care needs partner in decision making at all levels and are satisfied with the services they receive;
- Children and youth with special health care needs receive coordinated ongoing comprehensive care within a medical home;
- Families of CSHCN have adequate private and/or public insurance to pay for the services they need;
- Children are screened early and continuously for special health care needs;
- Community-based services for children and youth with special health care needs are organized so families can use them easily;
- Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

Maternal and Child Health Bureau

- Charged with providing services since 1935 through Title V of the Social Security Act
- 2004 Transitional Care became 1 of 6 Core Outcomes:

  "Youth with special health care needs will receive the services necessary to make appropriate transitions to adult health care, work and independence."

Scope of the Problem

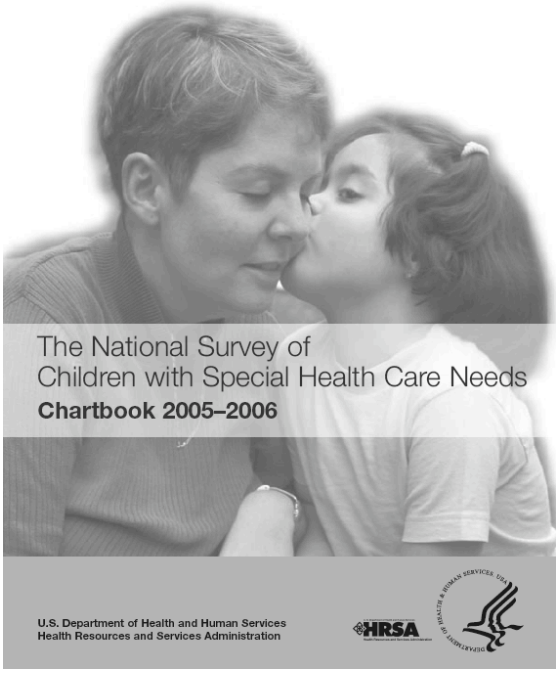
- 54 million people or 20% of the U.S. population
- 12 million children in the U.S.
- Costs $300 billion annually or 4% of the gross domestic product
- 50% of the cost is related to medical expenses
- 50% of the cost is related to lost productivity
- For the total population with disabilities there is an increased risk for secondary health problems due to lack of regular health promotion & screening.

Scope of the Problem

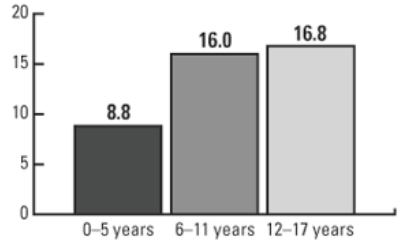
- 60% male
- 68% Non-Hispanic white
- 45% have "Medical Home" resources
- 84% have normal activities disrupted
- 42% have thought about shifting care
- 62% have "some knowledge" of anticipated health problems
- 34% have some knowledge of insurance issues

Scope of the Problem

- 78% of children with special health needs are encouraged to take responsibility for their own care
- Non-english speaking, low-income at greatest risk of not making successful transition
- Most significantly impacted by special health need also at risk for unsuccessful transitions
- Females more likely than males to have successful transitions

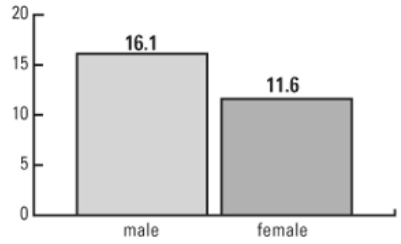


Prevalence of CSHCN: Age

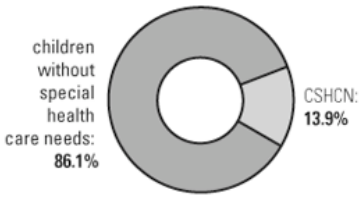


[D]

Prevalence of CSHCN: Sex

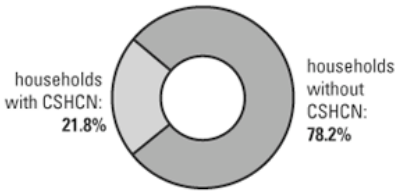


Prevalence of CSHCN: Individuals



[D]

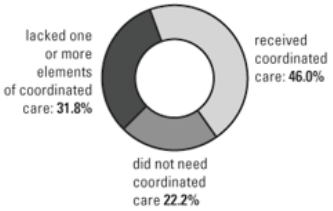
Prevalence of CSHCN: Households*



*Includes only households with children.

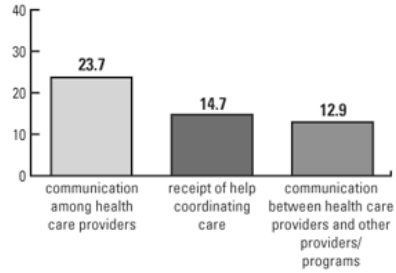
Percent of CSHCN Needing Specific Health Services	
Prescription drugs	86.4%
Preventive dental care	81.1%
Routine preventive care	77.9%
Specialty care	51.8%
Eyeglasses/vision care	33.3%
Mental health care	25.0%
Other dental care	24.2%
Physical, occupational, or speech therapy	22.8%
Disposable medical supplies	18.6%
Durable medical equipment	11.4%
Hearing aids/hearing care	4.7%
Home health care	4.5%
Mobility aids/devices	4.4%
Substance abuse treatment	2.8%
Communication aids/devices	2.2%

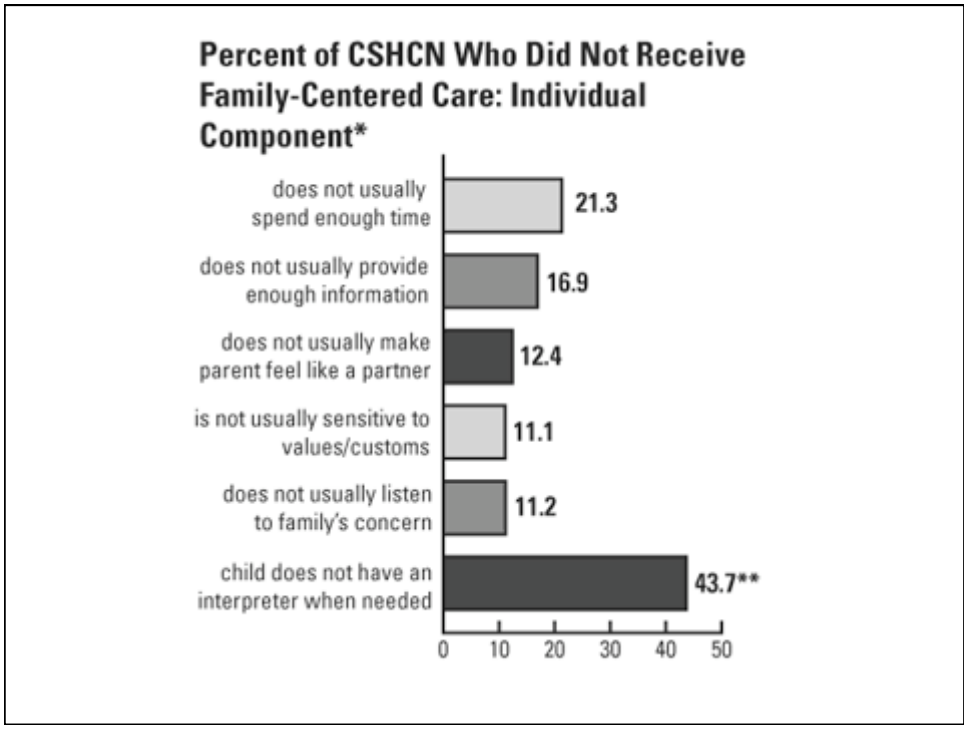
Receipt of Coordinated Care: CSHCN

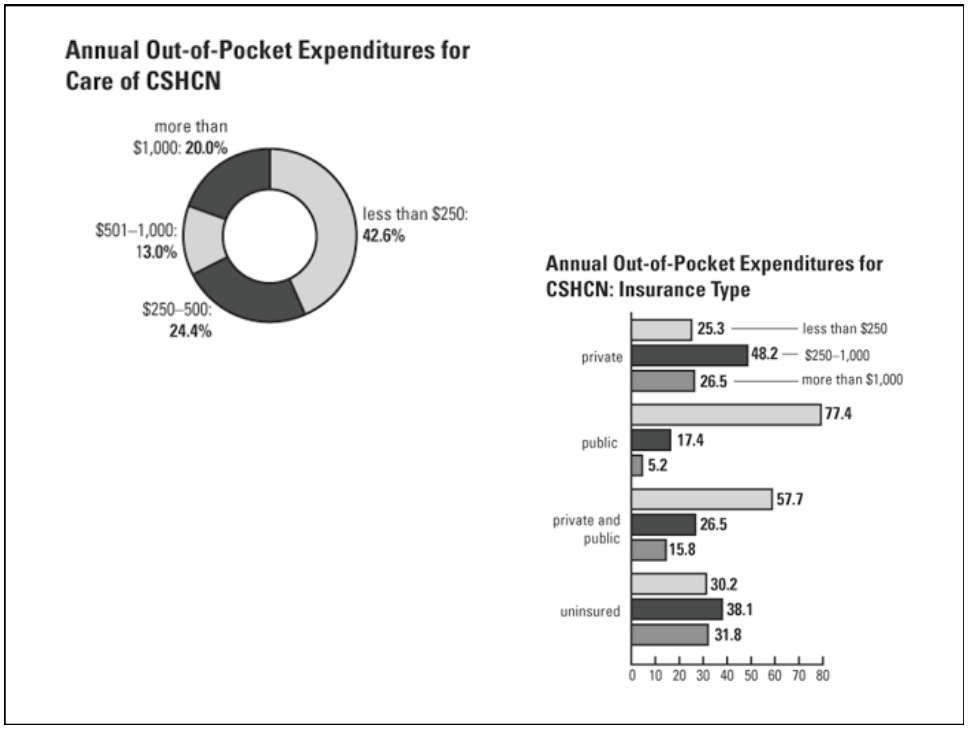


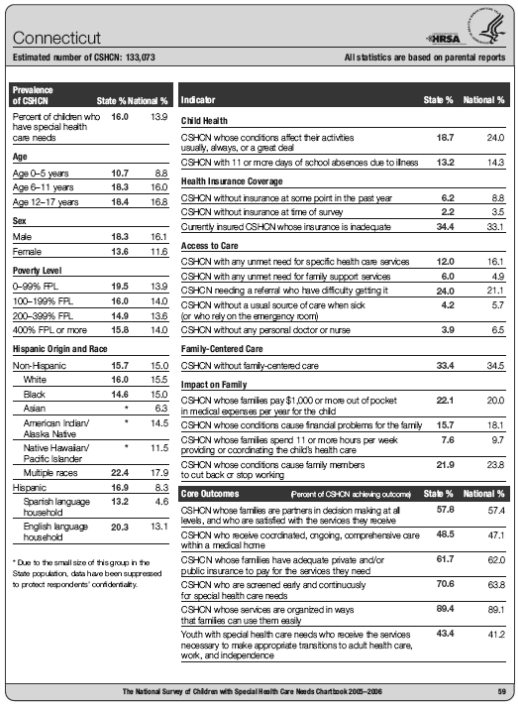
[D]

Percent of CSHCN Whose Care Did Not Meet Individual Care Coordination Components*




Percent of CSHCN Who Did Not Receive Family-Centered Care: Individual Component*
does not usually spend enough time
21.3
does not usually provide enough information
16.9
does not usually make parent feel like a partner
12.4
is not usually sensitive to values/customs
11.1
does not usually listen to family's concern
11.2
child does not have an interpreter when needed
43.7**
0 10 20 30 40 50


Annual Out-of-Pocket Expenditures for Care of CSHCN
more than $1,000: 20.0%
less than $250: 42.6%
$501–1,000: 13.0%
$250–500: 24.4%
Annual Out-of-Pocket Expenditures for CSHCN: Insurance Type
private
25.3
less than $250
48.2
$250–1,000
26.5
more than $1,000
public
77.4
17.4
5.2
private and public
57.7
26.5
15.8
uninsured
30.2
38.1
31.8
0 10 20 30 40 50 60 70 80



Connecticut

HRSA

Estimated number of CSHCN: 133,073

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	16.0	13.9
Age		
Age 0–5 years	10.7	8.8
Age 6–11 years	18.3	16.0
Age 12–17 years	18.4	16.8
Sex		
Male	18.3	16.1
Female	13.6	11.6
Poverty Level		
0–99% FPL	19.5	13.9
100–199% FPL	16.0	14.0
200–399% FPL	14.9	13.6
400% FPL or more	15.8	14.0
Hispanic Origin and Race		
Non-Hispanic	15.7	15.0
White	16.0	15.5
Black	14.6	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	22.4	17.9
Hispanic	16.9	8.3
Spanish language household	13.2	4.6
English language household	20.3	13.1

* Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.

Indicator	State %	National %
Child Health		
CSHCN whose conditions affect their activities usually, always, or a great deal	18.7	24.0
CSHCN with 11 or more days of school absences due to illness	13.2	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	6.2	8.8
CSHCN without insurance at time of survey	2.2	3.5
Currently insured CSHCN whose insurance is inadequate	34.4	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	12.0	16.1
CSHCN with any unmet need for family support services	6.0	4.9
CSHCN needing a referral who have difficulty getting it	24.0	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	4.2	5.7
CSHCN without any personal doctor or nurse	3.9	6.5
Family-Centered Care		
CSHCN without family-centered care	33.4	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	22.1	20.0
CSHCN whose conditions cause financial problems for the family	15.7	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	7.6	9.7
CSHCN whose conditions cause family members to cut back or stop working	21.9	23.8
Core Outcomes (Percent of CSHCN achieving outcome)	**State %**	**National %**
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	57.8	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	48.5	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	61.7	62.0
CSHCN who are screened early and continuously for special health care needs	70.6	63.8
CSHCN whose services are organized in ways that families can use them easily	89.4	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	43.4	41.2

The National Survey of Children with Special Health Care Needs Chartbook 2005–2006 59

Considerations

- Assume responsibility for personal care
- Anticipate future health needs
- Obtain future healthcare providers
- Plan for Health Insurance changes

PCP – Medical Home

- Patient Safety
- Effectiveness*
- Efficiency
- Family-Provider Partnership*
- Health Status*
- Timeliness*
- Equity
- Cost*

PCP – Medical Home

- Effectiveness
  - Adherence to plan of care (medications, diet)
  - Fewer hospitalizations and/or decreased length of stay
  - Fewer ED visits
- Family-Provider Partnership
  - Increased Self management
  - Improved Satisfaction
  - Decreased Family stress/improved Family functioning
- Health Status
  - Fewer School or Work days missed
  - Fewer unmet needs

PCP – Medical Home

- Timeliness
  - Less time to have phone calls returned
  - Less time to get an appointment
  - Same day appointment availability
  - Access to Provider after hours
- Cost
  - Decreased Short-term costs
  - Decreased Long-term costs

The Hand-off:

Goal is a seemless hand-off

- Traditional separation of Pediatric and Adult care
- Internal Medicine specialists most comfortable with disorders they see in Adult patients already: Diabetes, Obesity, Cancer, Intellectual disability etc…
- Lack of preparation at the receiving end
- Lack of knowledge at the hand-off end

The Hand-off:

Goal is a seemless hand-off

- Emotional Rapport between Pediatric Providers & families is a strength & weakness
- Reimbursement and Administrative Barriers to Co-management
- Models exist:
  - Geriatric-End of Life Case Management
  - Childhood Cancer Survivor care
  - Cystic Fibrosis
  - Congenital Heart Disease

Insurance Concerns:

Goal is continuous, uninterrupted coverage

- Life-time caps of expenditures
- Confusion about coverage since some private insurers cover children still in school until 22 years of age
- Medicaid Waivers end at 18 years of age
- SSI/Disability can start at 18 years of age

New Insurance Trends:

- "Ticket to Work" Programs
  - Meet SSI criteria, able to work however not able to make sufficient pay to meet needs
- Adult Disabled Dependent Child clauses
  - Must prove life-long disability
  - No ability for substantial gainful employment
  - Requires annual recertification
- Court ordered benefits
  - Need time-frame specified

New Insurance Trends:

- Raising the Age of dependency
  - Applies to single children without children of their own
  - 24 years in DE, IN & SD*
  - 25 years in CO, ID, ME, MD, MT, NM, RI, TX, VA, WA, WV
  - 26 years in CT, MA, NH, UT
  - 30 years in NJ, SD with Employer support*
  - PENDING laws in AK, CA, FL, MN, MO, NV, NY, PA, OH, TN

What is needed ?

- Children with Special Health Care needs
- Parents/Guardianship
- PCP (Medical Home)
- Current Specialists
- Professional Organizations
- State & Federal Resources

Role of Child with the Special Health Need

- Be aware of Age of Majority
- Learn about their health care needs
- Actively participate in keeping themselves healthy
- Acquire necessary skills to implement the health care plan
- Become their own advocate
- Be able to obtain all necessary services

Parents Role

Teach, encourage as we do with every other transition

- Call for an appointment, lab test or to refill a medication
- Arrange transportation
- Know Medications & dosages like you know your address & phone number
- Dispense medications, mix formulas, cook meal for the family, make lunch for school or work
- Discuss sexuality & pregnancy
- Have an emergency plan in place

Birth to Three

- Develop trust
- Take breaks to maintain your energy & health
- Begin record keeping of early childhood interventions, medical history, surgeries and injuries, immunizations, medications, special diets, allergies & adverse drug events
- Create list of Specialists involved in your child's care
- Apply for Medicaid Waiver whenever possible

Three to Five

- Develop decision-making skills by offering choices
- Encourage participation in household chores
- Get involved in recreational & community activities
- Begin to teach self-care related to chronic illness
- Encourage interaction with therapists, nurses & doctors
- Begin teaching about personal space & relationships
- "What do you want to do when you grow up?"

Six to Eleven

- Strengthen knowledge of chronic illness
- Strengthen self-care abilities
- Discuss personal safety
- Consider 504 Plan or IEP needs
- Encourage Hobbies & Leisure activities
- Begin shopping with the child
- Discuss consequences of poor choices
- Teach self-advocacy skills

Twelve to Eighteen

- Fill in gaps about special health needs
- Encourage self-care
- Include adolescent in 504 & IEP plans
- Support ordering their own medications & supplies, calling for appointments etc…
- Discuss sexuality
- Consider special needs Camp attendence
- Explore insurance changes
- Plan for Provider changes

Yale University School of Medicine

AUTHORIZATION FOR RELEASE OF PROTECTED HEALTH INFORMATION TO A PERSONAL REPRESENTIVE

This Authorization grants permission to the Personal Representative named below to have access to my Protected Health Information.
I hereby authorize (Department & Physician Name) _____ to use and disclose my Protected Health Information. I understand that this authorization is voluntary. I understand that once this information is released to the Designated Party named below, the released information may no longer be protected by federal privacy regulations.

Patient name: _____ IDX #: _____ DOB _____

Designated party _____ Relationship to Patient: _____

Address: _____ Phone: _____

The information will be used or disclosed for the following purposes:
❑ At the request of the individual ❑ Other: _____

Please read the three statements below carefully before signing this document:

1. I understand that I may revoke this Authorization at any time by notifying the ***Deputy Privacy Officer, Yale School of Medicine, 300 George Street, 6th Floor, New Haven, CT 06536*** in writing; however, if I do revoke the authorization, it will not have any affect on any actions taken by ***Yale School of Medicine*** prior to their receipt of the revocation.
2. I understand that my treatment or payment for treatment cannot be conditioned on whether or not I sign this Authorization:
3. I understand that this Authorization will: (***Must check one***)
   ( ) expire 1 year from the date executed; or
   ( ) be effective for the lifetime of the patient unless revoked (see #1 above)

_____
Signature of Patient

I understand that this health information may include HIV-related information and/or information relating to diagnosis or treatment of psychiatric disabilities and/or substance abuse and that by signing this form, I am specifically authorizing the release of information relating to:
__ Substance Abuse (including alcohol/drug abuse)
__ Mental Health
__ Psychotherapy Notes
__ HIV related information (including AIDS related testing)

The confidentiality of this record is required under Chapter 899 of the Connecticut General Statutes, as well as, Title 42 of the United States code. This material shall not be transmitted to anyone without written consent or authorization as provided in these statutes.

_____
Signature of Patient

_____ Date: _____
Signature of patient representative
(Form will not be valid unless all appropriate blanks are filled)

Printed Name of Patient's Representative: _____

Relationship to Patient: _____

YOU MAY REFUSE TO SIGN THIS AUTHORIZATION

After Eighteen

- Assume for responsibility for getting health needs met
- Parent should remain resource & social support
- Continue Hobbies & leisure activities
- Encourage Support Group involvement
- Connect to community-based or college-based disability services
- Consider contacting Department of Vocational Rehabilitation

Parents Role

Long-term Planning

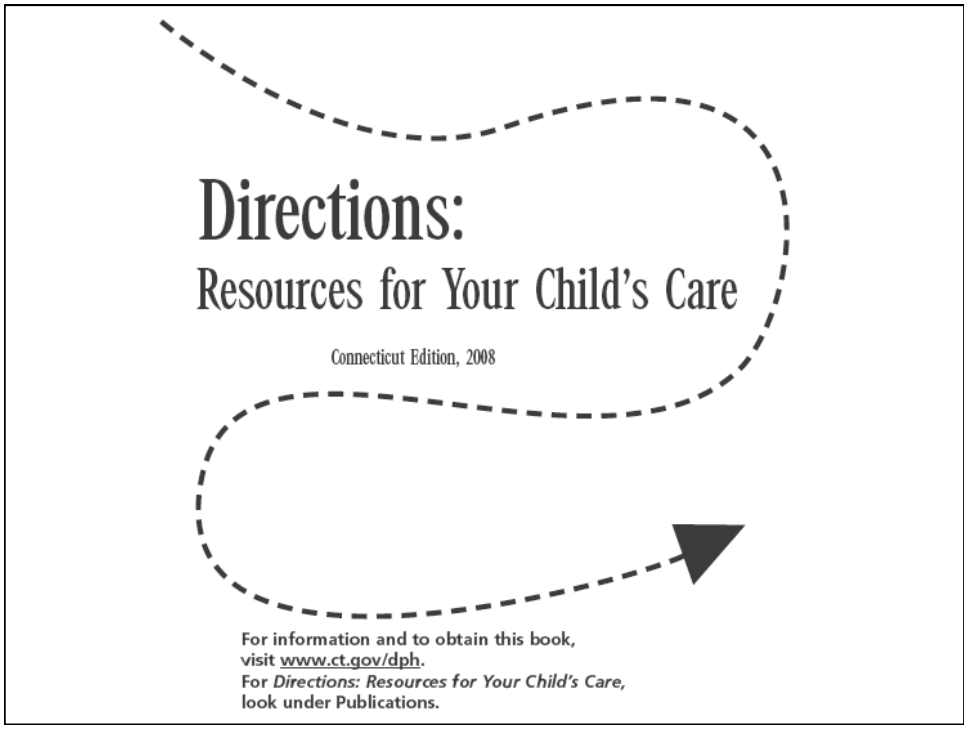
- Guardianship
- IEP inclusion
- Vocational training/other secondary education
- Supervised Living Arrangements
- Estate Planning

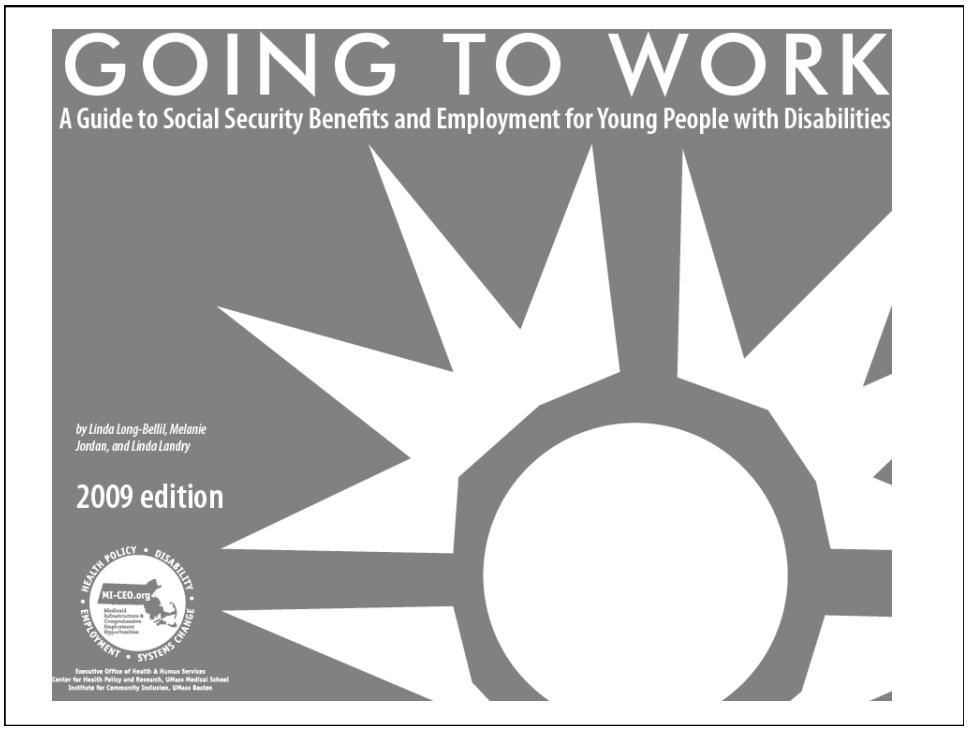
Barriers to the Medical Home and Transitional Care Movement

- Lack of Training
  - Specific conditions
  - Cultural Sensitivity
- Lack of Care Coordination Tools
- Lack of knowledge or access to Patient Registeries & Support organizations
- Lack of key personnel: Care Coordinator, Social Worker, Dietitian
- Time

Resources

- www.medicalhomeinfo.org
- www.familyvoices.org
- www.cms.hhs.gov/RealChoice/06_FamilytoFamily.asp
- www.socialsecurity.gov/disabilityresearch/youth.htm
- www.hdwg.org/cc
- http://depts.washington.edu/transmet


Directions:
Resources for Your Child's Care
Connecticut Edition, 2008
For information and to obtain this book,
visit www.ct.gov/dph.
For Directions: Resources for Your Child's Care,
look under Publications.


GOING TO WORK
A Guide to Social Security Benefits and Employment for Young People with Disabilities
by Linda Long-Bellil, Melanie Jordan, and Linda Landry
2009 edition
HEALTH POLICY • DISABILITY • EMPLOYMENT • SYSTEMS CHANGE
MI-CEO.org
Executive Office of Health & Human Services
Center for Health Policy and Research, UMass Medical School
Institute for Community Inclusion, UMass Boston

It's Time To Transition!

A Workbook for Young Adults, Their Families, and Their Medical Providers

Shared with Mountain States Regional Collaborative
2006